Access Revision (ACC)

Registry Sequence:
Date of Access Revision:

HEMODIALYSIS

1. Reason for hemodialysis access revisions:

Specify other reason for hemodialysis access revision:

<table>
<thead>
<tr>
<th>Reason for Hemodialysis Access Revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-0: Subject not on hemodialysis</td>
</tr>
<tr>
<td>1-1: Access infection</td>
</tr>
<tr>
<td>2-2: Access clotted</td>
</tr>
<tr>
<td>3-3: Access malfunction</td>
</tr>
<tr>
<td>4-4: Create more permanent access</td>
</tr>
</tbody>
</table>

*Additional Options Listed Below

2. External percutaneous catheter:

   If Yes, indicate:
   a. Vein:
   b. Lumen:

3. External arteriovenous shunt:

   If Yes, indicate Location:

4. Arteriovenous fistula:

   If Yes, indicate Location:

5. Arteriovenous graft:

   If Yes, indicate:
   a. Location:
   b. Graft type:

PERITONEAL DIALYSIS

6. Reason for peritoneal dialysis access revision:

Specify other reason for peritoneal access revision:

Describe new access:

<table>
<thead>
<tr>
<th>Reason for Peritoneal Dialysis Access Revision</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-1-Exit site/tunnel infection</td>
</tr>
<tr>
<td>2-2-Dialysate leak</td>
</tr>
<tr>
<td>3-3-Catheter malfunction</td>
</tr>
<tr>
<td>4-4-Peritonitis</td>
</tr>
</tbody>
</table>

*Additional Options Listed Below
7. Catheter:

8. Cuffs:

9. Tunnel:

10. Exit site points:

Comments:
Additional Selection Options for ACC

Reason for hemodialysis access revisions:
9-9-Other
## Targeted Adverse Event (ADV)

**Adverse Event:**

**Adverse Event Date:**

1. **If malignancy**, please specify diagnosis:

2. **If avascular necrosis or slipped capital femoral epiphyses**, record the following:
   - **Onset:** [ ] 1-Initial [ ] 2-Recurring
   - **X-ray confirmation:** [ ] 1-No [ ] 2-Yes
   - **Bone scan confirmation:** [ ] 1-No [ ] 2-Yes

3. **If intracranial hypertension**, record the following:
   - **Opening CSF pressure:** (xxx) mmH2O
   - **Headache:** [ ] 1-No [ ] 2-Yes
   - **Papilledema:** [ ] 1-No [ ] 2-Yes
   - **Nausea & vomiting:** [ ] 1-No [ ] 2-Yes
   - **Visual changes:** [ ] 1-No [ ] 2-Yes

4. **If serious adverse event**, please specify:

5. **If other adverse event**, please specify:

6. **Intensity:**
   - 1-1-Mild
   - 2-2-Moderate
   - 3-3-Severe
   - 4-4-Life-threatening

7. **Outcome:**
   - 1-1-Severe or permanent disability
   - 2-2-Death
   - 3-3-Neither

8. **Treatment required?**
   - **Hospitalization:** [ ] 1-No [ ] 2-Yes
   - **Medication:** [ ] 1-No [ ] 2-Yes
   - **Surgery:** [ ] 1-No [ ] 2-Yes
   - **Other treatment:** [ ] 1-No [ ] 2-Yes
   - **If other treatment, specify:** [ ]

9. **Was patient receiving growth hormone at the time of adverse event?**
   - **If receiving growth hormone, record the following:**
     - **Type:**
       - 1-1-Nutropin®
       - 2-2-Protropin®
       - 3-3-Humatrope®
       - 4-4-Nutropin Depot®
       - 9-9-Other
     - **Route**
       - 1-1-Subcutaneous
       - 2-2-Intraperitoneal
     - **Frequency:**
       - 1-1-Daily
       - 2-2-Every other day
       - 3-3-Three times/week
       - 4-4-Six times/week
       - 5-5-Weekly
     - **Dose:** (xx.xx) mg/dose
   - **If not receiving growth hormone, specify:** [ ]
e. Dosage of growth hormone was:

f. If dose changed, provide date:
   
   Did the adverse event abate?

  1-No     2-Yes

  If Yes, record date: (mm/dd/yyyy)

  1-No     2-Yes

  If Yes, did the adverse event recur?

  1-No     2-Yes

  If Yes, when? (mm/dd/yyyy)

10. Relationship to growth hormone:

   1-1-Not related- never received
   2-2-Not related
   3-3-Possible
   4-4-Probable

11. Comments:
Additional Selection Options for ADV

**Adverse Event (key field):**
1-1-Malignancy
2-2-Avascular necrosis
3-3-Slipped capital femoral epiphyses
4-4-Intracranial hypertension
5-5-Other serious adverse event
6-6-Other adverse event

**Frequency:**
6-6-Every other week
7-7-Monthly
9-9-Other
Cinacalcet Medication Log (CIN)

Registry Sequence:

If patient is on Cinacalcet prior to dialysis initiation, begin Cinacalcet log with dialysis initiation date and the dose at that time.

Please update when dose is changed or patient completes a cycle of therapy.

<table>
<thead>
<tr>
<th>Seq #</th>
<th>Start Date</th>
<th>Stop Date</th>
<th>Dose(mg)</th>
<th>Frequency</th>
<th>If frequency is other, explain:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-1: Once per day 2-2-2: Twice per day 3-3-1: Once a week 4-4-2: Twice a week 99-99-0: Other</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-1: Once per day 2-2-2: Twice per day 3-3-1: Once a week 4-4-2: Twice a week 99-99-0: Other</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-1: Once per day 2-2-2: Twice per day 3-3-1: Once a week 4-4-2: Twice a week 99-99-0: Other</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-1: Once per day 2-2-2: Twice per day 3-3-1: Once a week 4-4-2: Twice a week 99-99-0: Other</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-1: Once per day 2-2-2: Twice per day 3-3-1: Once a week 4-4-2: Twice a week 99-99-0: Other</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-1: Once per day 2-2-2: Twice per day 3-3-1: Once a week 4-4-2: Twice a week 99-99-0: Other</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-1: Once per day 2-2-2: Twice per day 3-3-1: Once a week 4-4-2: Twice a week 99-99-0: Other</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1-1-Once per day</td>
<td>2-2-Twice per day</td>
<td>3-3-Once a week</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>------------------</td>
<td>------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>8</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-Once per day</td>
<td>2-2-Twice per day</td>
</tr>
<tr>
<td>9</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-Once per day</td>
<td>2-2-Twice per day</td>
</tr>
<tr>
<td>10</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-Once per day</td>
<td>2-2-Twice per day</td>
</tr>
<tr>
<td>11</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-Once per day</td>
<td>2-2-Twice per day</td>
</tr>
<tr>
<td>12</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-Once per day</td>
<td>2-2-Twice per day</td>
</tr>
<tr>
<td>13</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-Once per day</td>
<td>2-2-Twice per day</td>
</tr>
<tr>
<td>14</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-Once per day</td>
<td>2-2-Twice per day</td>
</tr>
<tr>
<td>15</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-Once per day</td>
<td>2-2-Twice per day</td>
</tr>
<tr>
<td>16</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
<td>(xxx.x)</td>
<td>1-1-Once per day</td>
<td>2-2-Twice per day</td>
</tr>
</tbody>
</table>
Registration (DEM)

1. Does your site participate in the NAPRT CS Registries?  
   1- No  2- Yes
2. Date of birth:  
   (mm/dd/yyyy)
3. Race/ethnicity:  
   1-1-White  
   2-2-Black  
   3-3-Hispanic  
   9-9-Other
4. Gender:  
   1-Male  2-Female
5. Primary renal diagnosis:  
   If Other, specify diagnosis:
6. Biopsy or nephrectomy confirmation of diagnosis:
7. Maternal Paternal Education Score:  
   0-0-No formal education  
   1-1-Grade 6 or less  
   2-2-Grades 7-9  
   3-3-Grades 10 or more without diploma  
   4-4-Grade 12 (High school graduate)  
   *Additional Options Listed Below
8. Insurance Information:  
   Does patient have Medicaid?  1-No  2-Yes  9-Unknown  
   Does patient have supplemental private insurance?  1-No  2-Yes  9-Unknown
9. Has patient been transplanted prior to registration:  1-No  2-Yes
10. Total number of prior transplants:  
    (x)
11. Has patient ever received maintenance dialysis?  
    If Yes, specify date of first maintenance dialysis:  
    (xx) Month/ (xxxx) Year
12. ABO (record for Transplant and Dialysis participants):  
    1-A  2-B  3-O  4-AB
13. Histocompatibility data of recipient  
    Record for transplant participants:  
    HLA-A    A    (xx)    A    (xx)  
    HLA-B    B    (xx)    B    (xx)  
    HLA-DR   DR    (xx)    DR    (xx)  
    If assay performed but an allele was not determined, enter '99'
Additional Selection Options for DEM

Primary renal diagnosis:
06-06-Familial nephritis - Alport's Syndrome
07-07-Cystinosis
08-08-Oxalosis
09-09-Congenital nephrotic syndrome
10-10-Focal segmental glomerulosclerosis
11-11-Membranoproliferative glomerulonephritis - Type I
12-12-Membranoproliferative glomerulonephritis - Type II
13-13-Membranous nephropathy
14-14-Idiopathic crescentic glomerulonephritis
15-15-Chronic glomerulonephritis
16-16-Pyelonephritis/interstitial nephritis
17-17-Reflux nephropathy
18-18-SID w/SLE nephritis
19-19-SID w/Henoch-Schonlein purpura nephritis
20-20-SID w/Berger's nephritis (IgA)
21-21-SID w/Wegener's granulomatosis
22-22-SID w/other
23-23-Wilms' tumor
24-24-Renal infarct
25-25-Diabetic glomerulonephritis
26-26-Sickle cell nephropathy
27-27-Hemolytic uremic syndrome
28-28-Drash syndrome
30-30-Unknown
99-99-Other, specify

Education Score Maternal
5-5-Some college/ business/ vocational
6-6-College degree
7-7-Graduate work
9-9-Unknown
### Dialysis Status (DIA)

**Date of dialysis modality initiation:**

1. Date of evaluation: [ ]
   
2. Dry weight: [ ]
   
3. Height: [ ]
   
4. Blood pressure: [ ]

Check to unlock and change unit of measurement: [ ]

5. **CU** | **SL** | **Units**

   - Hematocrit: [ ] [ ] [%] [%]
   - Hemoglobin: [ ] [ ] [g/dL] [g/L]
   - Albumin: [ ] [ ] [g/dL] [g/L]
   - Inorganic phosphorus: [ ] [ ] [mg/dL] [mmol/L]
   - Calcium: [ ] [ ] [mg/dL] [mmol/L]

6. Most recent parathyroid hormone:
   a. Level: [ ] [pg/mL] [pmol/L]
   b. Lab normal (Upper Unit): [ ] [pg/mL] [pmol/L]

7. Tanner stage:
   - Pubic hair: [1-1] [2-2] [3-3] [4-4] [5-5]
   - Breast: [1-1] [2-2] [3-3] [4-4] [5-5]
   - Testicular size: [1-1] [2-2] [3-3] [4-4] [5-5]

8. Are anthropometric measures available? [ ]
   - If Yes, indicate:
     a. Mid arm circumference: [ ] [cm]
     b. Tricep skin fold thickness: [ ] [mm]

9. Type of dialysis:
   - [1-1-Peritoneal dialysis] [2-2-Hemodialysis]

10. If **HEMODIALYSIS**, indicate:
    a. Number of dialysis treatments per week: [ ]
    b. Hours/treatment: [ ]
    c. Is the patient receiving home hemodialysis? [ ]
    d. Most recent single pool Kt/V: [ ]
    e. URR: [ ]

11. If **PERITONEAL DIALYSIS**, indicate:
a. Current modality:
   1-1-CAPD
   2-2-APD
   3-3-IPD

b. Most recent weekly Kt/V: (x.x)

Medication Information
12. Is this patient currently participating in any Amgen clinical trials?  
   1-No  2-Yes
13. Is the patient receiving Cinacalcet?  
   1-No  2-Yes
14. Is the patient receiving erythropoietin?  
   If Yes, indicate:
   a. Type:
      1-1-Epogen®
      2-2-Procrit®
      3-3-Aranesp®
      9-9-Other
   b. Route:
      1-1-Subcutaneous
      2-2-Intraperitoneal
      3-3-Subcutaneous
   c. Frequency:
      1-1-Daily
      2-2-Three times/week
      3-3-Two times/week
      4-4-Weekly
      5-5-Weekly
   d. Dose: (xxxx.xx) Units
15. Is the patient receiving human growth hormone?  
   If Yes, indicate:
   a. Type:
      1-1-Nutropin®
      2-2-Protropin®
      3-3-Humatrope®
      4-4-Nutropin Depot®
      9-9-Other
   b. Route:
      1-1-Subcutaneous
      2-2-Intraperitoneal
   c. Frequency:
      1-1-Daily
      2-2-Every other day
      3-3-Three times/week
      4-4-Six times/week
      5-5-Weekly
      *Additional Options Listed Below
   d. Dose: (xx.xx) mg

16. Concomitant Drug Therapy
   a. Sevelamer hydrochloride/Sevelamer carbonate  
      1-No  2-Yes
   b. Anticonvulsant  
      1-No  2-Yes
   c. Anti-hypertensives  
      1-No  2-Yes  If Yes, number of drugs: (x)
   d. Calcium acetate  
      1-No  2-Yes
   e. Calcium carbonate  
      1-No  2-Yes
   f. Other calcium supplements  
      1-No  2-Yes
   g. Immunosuppressives  
      1-No  2-Yes
   h. Iron - oral  
      1-No  2-Yes
   i. Iron - IV  
      1-No  2-Yes
   j. Nutrition - enteral  
      1-No  2-Yes
   k. Nutrition - parenteral  
      1-No  2-Yes
l. Prophylactic antibiotics
   1- No  2- Yes
m. 1,25-dihydroxy Vitamin D - oral
   1- No  2- Yes
n. 1,25-dihydroxy Vitamin D - IV
   1- No  2- Yes
o. Other Vitamin D compounds
   1- No  2- Yes
p. Lipid lowering agents
   1- No  2- Yes
q. Paricalcitol IV
   1- No  2- Yes
r. Paricalcitol PO
   1- No  2- Yes
s. Doxercalciferol IV
   1- No  2- Yes
t. Doxercalciferol PO
   1- No  2- Yes

Events Information

17. Has the patient had seizures since the last report?  1- No  2- Yes  9- Unknown
   a. Number days with one or more seizures: 

<table>
<thead>
<tr>
<th>Episode #1</th>
<th>Episode #2</th>
<th>Episode #3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date:</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
</tr>
<tr>
<td>Was patient hospitalized?</td>
<td>1- No  2- Yes</td>
<td>1- No  2- Yes</td>
</tr>
<tr>
<td>How many days in hospital?</td>
<td>(xxx)</td>
<td>(xxx)</td>
</tr>
<tr>
<td>Was patient on Cinacalcet at time of this event?</td>
<td>1- No  2- Yes</td>
<td>1- No  2- Yes</td>
</tr>
</tbody>
</table>

Comments: 

18. Has patient been treated for or had a modification of treatment for hypocalcemia since last report?  1- No  2- Yes  9- Unknown
   - IV Calcium supplementation: 
   - Oral calcium supplementation: 
   - Vitamin D supplementation: 
   - Modification to Cinacalcet therapy? 
   - Other: 

<table>
<thead>
<tr>
<th>Episode #1</th>
<th>Episode #2</th>
<th>Episode #3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date:</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
</tr>
<tr>
<td>Treatment/Therapy Change</td>
<td>1- No  2- Yes</td>
<td>1- No  2- Yes</td>
</tr>
<tr>
<td>a. IV Calcium supplementation:</td>
<td>1- No  2- Yes</td>
<td>1- No  2- Yes</td>
</tr>
<tr>
<td>b. Oral calcium supplementation:</td>
<td>1- No  2- Yes</td>
<td>1- No  2- Yes</td>
</tr>
<tr>
<td>c. Vitamin D supplementation:</td>
<td>1- No  2- Yes</td>
<td>1- No  2- Yes</td>
</tr>
<tr>
<td>d. Modification to Cinacalcet therapy?</td>
<td>1- No  2- Yes</td>
<td>1- No  2- Yes</td>
</tr>
<tr>
<td>e. Other:</td>
<td>1- No  2- Yes</td>
<td>1- No  2- Yes</td>
</tr>
<tr>
<td>Was patient hospitalized?</td>
<td>1- No  2- Yes</td>
<td>1- No  2- Yes</td>
</tr>
<tr>
<td>Days hospitalized?</td>
<td>(xxx)</td>
<td>(xxx)</td>
</tr>
<tr>
<td>Was patient on Cinacalcet at time of the event?</td>
<td>1- No  2- Yes</td>
<td>1- No  2- Yes</td>
</tr>
</tbody>
</table>

Comments: 

19. Has the patient been hospitalized for infection since last report?  1- No  2- Yes  9- Unknown
   
<table>
<thead>
<tr>
<th>Episode #1</th>
<th>Episode #2</th>
<th>Episode #3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date:</td>
<td>(mm/dd/yyyy)</td>
<td>(mm/dd/yyyy)</td>
</tr>
</tbody>
</table>
### Type of Infection:

<table>
<thead>
<tr>
<th></th>
<th>a. Bacterial:</th>
<th>b. Viral:</th>
<th>c. Fungal:</th>
<th>d. Other:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1- No</td>
<td>2- Yes</td>
<td>1- No</td>
<td>2- Yes</td>
</tr>
</tbody>
</table>

### Days hospitalized:

|   | (xxx) | (xxx) | (xxx) |

### Was patient on Cinacalcet at time of the event?

|   | 1- No | 2- Yes |

### Comments:

- 20. Has the patient had blood transfusions since the last report?
  - 1- No
  - 2- Yes
  - 9- Unknown
  - If Yes, how many episodes? (x)

- 21. Number of peritonitis episodes since the last report:
  - (x)

### Peritonitis Episodes - Indicate type and date of infection onset

<table>
<thead>
<tr>
<th>Episode</th>
<th>Type</th>
<th>Date of Onset (mm/dd/yyyy)</th>
<th>Cell Count (WBC/mm³)</th>
<th>Cell Differential (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1-1 Fungal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>1-1 Fungal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>1-1 Fungal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>1-1 Fungal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>1-1 Fungal</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Additional Options Listed Below*
22. Has the patient had an access site infection since the last report? □ 1-No  □ 2-Yes

Hospitalization Information
23. Total days hospitalized since the last report: □ 1-No  □ 2-Yes
   If hospitalized since last report, indicate reason(s):
   a. Infection: □ 1-No  □ 2-Yes
   b. Access complications/catheter malfunction: □ 1-No  □ 2-Yes
   c. Hypertension: □ 1-No  □ 2-Yes
   d. Other cardiovascular: □ 1-No  □ 2-Yes
   e. Dialysis initiation: □ 1-No  □ 2-Yes

24. Has the patient had an echocardiogram performed since the last report? □ 1-No  □ 2-Yes
   If yes, □ 1-No  □ 2-Yes
   a. Absolute LV mass: □ 1-No  □ 2-Yes
   b. LVM Index units: □ 1-gm/m²  □ 2-gm/m²
   c. LVM Index: □ 1-No  □ 2-Yes

Education Information
25. Has the patient completed high school education? □ 1-No  □ 2-Yes
   If No, indicate one of the following:
   1-1-Attends school full time
   2-2-Attends school part-time
   3-3-Received home schooling only
   4-4-Not attending school, medically capable
   5-5-Not attending school, medically incapable
   *Additional Options Listed Below

26. Is the patient participating in a formal adult transition program? □ 1-No  □ 2-Yes

Transplant Status
27. Indicate the current transplant status:
   □ 1-No  □ 2-Yes
   1-1-On cadaver waiting list
   2-2-Not on list, transplant preparation/workup in progress
   3-3-Not on list, medical reason
   4-4-Not on list, family/patient preference
   *Additional Options Listed Below

28. Most recent PRA sensitization:
   □ 1-No  □ 2-Yes

Comments:
Additional Selection Options for DIA

Pubic hair:
6-6-Unknown

Testicular size:
6-6-Unknown

Frequency:
6-6-Every other week
7-7-Monthly
9-9-Other

Peritonitis type 1
7-7-No culture
9-9-Other

If No, indicate one of the following:
6-6-Not of school age
Patient Death (DTH)

1. Date of death: [ ]

2. Cause of death:
   - 01-01: Infection, viral
   - 02-02: Infection, bacterial
   - 03-03: Infection, not specified
   - 04-04: Cancer/malignancy
   - 05-05: Cardiopulmonary
   *Additional Options Listed Below*

   If other, specify cause of death: [ ]

3. Graft status at death:
   - 1-1: Functioning
   - 2-2: Non-functioning
   - 3-3: Not applicable

4. Comments: [ ]
Additional Selection Options for DTH

Cause of death:
06-06-Hemorrhage
07-07-Recurrence of original renal disease
08-08-Dialysis-related complications
09-09-Other, specify
10-10-Unknown
1. If you want to enroll the participant in to the Dialysis Registry, enter the Date of Dialysis Initiation:  

2. If you want to enroll the participant in to the Dialysis Registry, enter the Date of Dialysis Initiation:  

3. Date of 30 day followup evaluation:  

   Patients must have a 30 day evaluation to be considered eligible for the Dialysis Registry.
Lost to Follow Up (LTF)

1. Date lost to follow up:  
2. Reason for loss:  
   - If Other, specify:  
3. Graft status at loss:  
   - If Other, specify:  
4. Comments:
Additional Selection Options for LTF

Reason for loss:
8-8-Administrative Closure
9-9-Other
Malignancy Form (MAL)

Malignancy date:

1. Type of malignancy:
   - 1-1-Hematologic/Lymphoid
   - 2-2-Solid tumor
   - 3-3-Skin (non-melanoma)
   - 9-9-Other

2. Specify malignancy:

3. Is this malignancy a PTLD?
   - 1-No
   - 2-Yes

If this malignancy is a "PTLD", please complete the remainder of form.

4. Height at diagnosis of PTLD:
   
5. Weight at diagnosis of PTLD:
   
6. Type of PTLD:
   - 1-1-Polymorphic
   - 2-2-Monomorphic
   - 9-9-Unknown

7. Clonality:
   - 1-1-Polyclonal
   - 2-2-Monoclonal
   - 9-9-Unknown

8. Cell type:
   - 1-T-Cell
   - 2-B-Cell
   - 9-Other, specify

   a. If "Other", specify:

   b. PTLD pathology Epstein-Barr virus stain (EBER or LMP):
      - 1-Positive
      - 2-Negative
      - 9-Unknown/Not done

   c. PTLD pathology CD 20 stain:
      - 1-Positive
      - 2-Negative
      - 9-Unknown/Not done

9. Location of PTLD:
   a. Allograft
      - 1-No
      - 2-Yes
   b. Lymph node
      - 1-No
      - 2-Yes
   c. Central nervous system
      - 1-No
      - 2-Yes
   d. Other
      - 1-No
      - 2-Yes

   1. If "Other", specify

10. Pre-transplant EBV serology:
    a. Donor:
       - 1-Positive
       - 2-Negative
       - 9-Unknown/Not done
    b. Recipient:
       - 1-Positive
       - 2-Negative
       - 9-Unknown/Not done

11. Serum creatinine at diagnosis of PTLD:
    - (xx.x) mg/dl OR (xxxx.x) µmol/L

12. Last prior serum creatinine value (3 months before diagnosis):
    - (xx.x) mg/dl OR (xxxx.x) µmol/L

13. Date of last prior serum creatinine value:
    - (mm/dd/yyyy)

Intervention Data

14. Reduction of Immunosuppression:
    - 1-No
    - 2-Yes

   a. If "Yes", specify type(s) of reduction:

15. Anti-CD20 antibody use:
    a. If "Yes", number of doses:
       - (xxx)
    b. Total dose administered:
       - (xxxx.xx) mg

16. Alpha interferon use:
    a. If "Yes", number of doses:
       - (xxx)
    b. Total dose administered:
       - (xxxx.xx) mg
17. Chemotherapy used:  1-No     2-Yes
   a. If "Yes", regimen used:
   b. If "Yes", number of cycles:
   c. If "Yes", duration of therapy in months:

18. Anti-viral therapy use:  1-No     2-Yes
   a. If "Yes", agent used:
   b. Dose administered:
   c. Duration of therapy:

19. Surgical reduction of mass:  1-No     2-Yes
   a. If "Yes", allograft nephrectomy:  1-No     2-Yes

20. Concomitant rejection treatment:  1-No     2-Yes
   a. If "Yes", agent used:

21. Outcome Data

22. Viral load by PCR:  1-No     2-Yes
   a. If "Yes", value at diagnosis:
   b. If "Yes", value at 1 month after diagnosis:
   c. If "Yes", value at time of increase in immunosuppression:

23. Serum creatinine after PTLD treatment:
   (xx.x) mg/dl OR (xxx.x) µmol/L

24. Date of serum creatinine after treatment:
   (mm/dd/yyyy)

25. Graft loss:  1-No     2-Yes
   a. If "Yes", date:

26. Date immunosuppression increased again:

27. Immunosuppression after PTLD resolution:  1-No     2-Yes

<table>
<thead>
<tr>
<th>Agent</th>
<th>Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prednisone</td>
<td>(xx.x)</td>
</tr>
<tr>
<td>Cyclosporine</td>
<td>(xxx.x)</td>
</tr>
<tr>
<td>Tacrolimus</td>
<td>(xxx.x)</td>
</tr>
<tr>
<td>Sirolimus</td>
<td>(xxx.x)</td>
</tr>
<tr>
<td>Mycophenolate mofetil</td>
<td>(xxxx.x)</td>
</tr>
<tr>
<td>Azathioprine</td>
<td>(xxx.x)</td>
</tr>
</tbody>
</table>

28. Retransplant after PTLD:  1-No     2-Yes
   a. If "Yes", date of retransplant:

29. Recurrence of PTLD in retransplant:  1-No     2-Yes
   a. If "Yes", date of recurrence:

Comments:
Dialysis Modality Initiation (MDI)

Registry Sequence:

Date of initiation of CURRENT dialysis modality:

1. Has the patient had all PRIOR RENAL TRANSPLANTS removed?  1-No  2-Yes  3-Not applicable
2. Has the patient had all NATIVE renal tissue removed?  1-No  2-Yes

Dialysis Data

3. Dialysis modality of this initiation:
   1-1-Peritoneal dialysis
   2-2-Hemodialysis

4. Provide number of consecutive days of hospitalization from initiation of dialysis treatment until discharge: (xxx)

Check to unlock and change unit of measurement:

5. CU  SI  Units
   Serum creatinine at initiation: (x.x) (xxxx.x)  mg/dL  µmol/L

Access Used For Maintenance Dialysis at Registration

Hemodialysis - Indicate only ONE Access

6. External percutaneous catheter:  1-No  2-Yes
   If Yes, indicate:
   a. Vein:
      1-1-Subclavian
      2-2-Jugular
      3-3-Femoral
   b. Lumen:
      1-Single  2-Double

7. External arteriovenous shunt:
   If Yes, indicate Location:
   1-1-Upper Arm
   2-2-Lower Arm
   3-3-Thigh
   9-9-Other

8. Arteriovenous fistula:
   If Yes, indicate Location:
   1-1-Upper Arm
   2-2-Lower Arm
   3-3-Thigh
   9-9-Other

9. Arteriovenous graft:
   If Yes, indicate:
   a. Location:
      1-1-Upper Arm
      2-2-Lower Arm
      3-3-Thigh
      9-9-Other
   b. Specify graft type:
      1-1-Autologous vein
      2-2-Bovine
      3-3-PTFE [Gore-Tex®]
      9-9-Other
Peritoneal Dialysis:

10. Catheter:

11. Cuffs:  
- One
- Two

12. Tunnel:
- Swan neck
- Straight

13. Exit site points:
- Up
- Down
- Lateral
- Unknown

14. Comments:
Dialysis Modality Termination (MDL)

Registry Sequence:

1. Date of dialysis modality termination:
[ ]

2. Reason to close this dialysis segment:
   - 1-1-Patient was transplanted (Submit Transplantation Report Form)
   - 1-2-Patient was switched to another dialysis regimen (Submit Dialysis Initiation Form)
   - 2-3-Patient died (Submit Death Form)
   - 4-4-Native kidney function returned
   - 8-8-Administrative Closure
   *Additional Options Listed Below

3. If surviving patient was NOT transplanted, specify reason for termination:
   - 1-1-Excessive infection
   - 2-2-Patient/family choice; inability to cope
   - 3-3-Access failure
   - 4-4-Inadequate ultrafiltration
   - 5-5-Inadequate solute clearance
   *Additional Options Listed Below

Comments:
Additional Selection Options for MDL

Reason to close this dialysis segment:
9-9-Other, specify

If surviving patient was NOT transplanted, specify reason for termination:
6-6-Excessive hospitalization for dialysis-related complications
7-7-Excessive hospitalization for other than dialysis-related complications
8-8-Other [medical], specify
9-9-Other [nonmedical], specify